Implementing Health Reform: Improved Data Collection and the Monitoring of Health Disparities

Rashida Dorsey,¹ Garth Graham,² Sherry Glied,³ David Meyers,⁴ Carolyn Clancy,⁵ and Howard Koh⁶

¹Office of Minority Health, U.S. Department of Health and Human Services, Rockville, Maryland 20852; email: Rashida.Dorsey@hhs.gov
²Department of Medicine, University of Florida, Gainesville, Florida 32611; email: Garth.Graham@medicine.ufl.edu
³Wagner Graduate School of Public Service, New York University, New York, NY 10012-9604; email: sherry.glied@nyu.edu
⁴Agency for Healthcare Quality and Research, U.S. Department of Health and Human Services, Rockville, Maryland 20850; email: David.Meyers@ahrq.hhs.gov
⁵Office of Quality, Safety and Value, Department of Veterans Affairs, Washington, DC 20420; email: Carolyn.Clancy@va.gov
⁶Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services, Washington, DC 20201; email: Howard.Koh@hhs.gov

Keywords
data standards, Affordable Care Act, demographic data, population-based surveys

Abstract
The relative lack of standards for collecting data on population subgroups has not only limited our understanding of health disparities, but also impaired our ability to develop policies to eliminate them. This article provides background about past challenges to collecting data by race/ethnicity, primary language, sex, and disability status. It then discusses how passage of the Affordable Care Act has provided new opportunities to improve data-collection standards for the demographic variables of interest and, as such, a better understanding of the characteristics of populations served by the U.S. Health and Human Services (HHS). The new standards have been formally adopted by the Secretary of HHS for application in all HHS-sponsored population health surveys involving self-reporting. The new data-collection standards will not only promote the uniform collection and utilization of demographic data, but also help the country shape future programs and policies to advance public health and to reduce disparities.
INTRODUCTION

Healthy People 2020 promotes the elimination of health disparities as an overarching goal for the next decade and beyond. But attaining this goal has been challenging and elusive (69, 83). A health disparity is a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health on the basis of their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (69).

Disparities and differences in health and health care have been well documented not only by race and ethnicity, but also by language, sex, and disability status. For example, on average, racial and ethnic minorities are more likely than whites to be uninsured (67) and also to have higher rates of illness and death from conditions such as heart disease, stroke, specific cancers, diabetes, HIV/AIDS, asthma, hepatitis B, and overweight and obesity compared with the rest of the US population (2, 11, 12, 22, 27, 48, 61, 63, 66, 82, 99). In addition, people who speak a language other than English face significant barriers in access to care and in receiving quality health care (3, 4, 15, 16, 19, 23, 24, 26, 30–34, 50, 54, 86). Health outcomes and care received also vary between men and women (5, 18, 20, 43, 51, 57, 62, 75, 93, 98, 102). Finally, people with disabilities frequently cannot access the benefits, services, and information provided by health care systems to the same extent as those without disabilities (29, 46, 53, 55, 77, 92, 95).

Many of these disparities could be ameliorated through enhanced access and quality of care for population subgroups. The enactment of the Patient Protection and Affordable Care Act offers new opportunities in this regard. The Affordable Care Act enacted comprehensive health insurance reforms and contains specific provisions to improve federal, state, and local efforts to address the health concerns of underserved communities (39). First, of course, these provisions include providing many Americans opportunities for health insurance coverage and access to certain preventive services without cost-sharing requirements. Also of great importance, they require data-collection standards to better identify key population subgroups that may benefit from key Affordable Care Act implementation themes, such as targeted outreach for education and enrollment and monitoring of the long-term impact on disparities in the United States. Thus, strengthening data-collection efforts ranks as a critical part of Affordable Care Act implementation.

In this article, we first provide background on the need for data-collection standards for key demographic variables. We then discuss how passage of the Affordable Care Act has made the promulgation of data-collection standards possible for race, ethnicity, sex, primary language, and disability status and how such data are critical to track long-term impacts of the key Affordable Care Act provisions for population subgroups. We close with a discussion about implications for improved disparities-reduction efforts for the future.

THE NEED FOR DATA-COLLECTION STANDARDS

For too long, the absence of data-collection standards for population subgroups has inhibited uniform reporting and tracking of health disparities data. Over time, researchers have increasingly recommended standardizing the collection of such critical information to prompt a better understanding of the barriers related to race and ethnicity, language, disability status, and sex and to stimulate strategies to overcome them (6, 8, 37, 38, 56, 59, 60, 76, 79, 84). Landmark reports, such as the Institute of Medicine’s (IOM) Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, which have identified multiple factors slowing progress toward the elimination of
health disparities among racial and ethnic minority groups, have regularly expressed concern about the lack of consistency and granularity in the collection of data on racial and ethnic minorities (19). In 2009, at the request of the Agency for Healthcare Research and Quality, the IOM formed the Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality. The subsequent Subcommittee report, *Race, Ethnicity, and Language Data Collection: Standardization for Health Care Quality Improvement*, emphasized that the lack of standardized data relevant to race, ethnicity, and language diminished the likelihood that effective actions could be identified to reduce specific health disparities (86). The Subcommittee recommended that standardization of data collection should expand beyond the existing 1997 Office of Management and Budget’s (OMB) race and Hispanic ethnicity categories to include, at a minimum, collection of data on more fine-grained categories of ethnicity (“granular ethnicity,” based on one’s ancestry) and language (a rating of one’s spoken English language proficiency and one’s preferred language for health-related encounters).

The increasing diversity of the US population also supports the need for adding specificity to race/ethnicity data-collection efforts and for establishing data-collection standards for primary language, disability status, and sex. According to data collected by the U.S. Census Bureau in 2010, 36.3% of the population identifies as being part of a racial or ethnic minority group, 19.7% report speaking a language other than English at home, and 18.7% report some form of disability (10, 45, 81). Rising diversity within existing categories of minority populations and an increase in the number of people who self-identify as multiracial [see the review by Mays et al. on federal data collection (7, 58)] also pose challenges for data collection.

In summary, there is a great awareness of the importance of collecting reliable data on specific racial and ethnic subpopulations beyond the 1997 OMB-established minimum categories of race and ethnicity (49, 85, 94, 96). Ongoing research continues to explore the optimal ways to collect data on race and ethnicity. For example, in a comprehensive review of federal data collection on race and ethnicity, Mays et al. noted that changing demographics can make past categorizations inadequate, especially because more Americans trace their roots to multiracial or multiethnic sources (7, 58). In addition, standardizing demographic data collection and developing more granular categories can aid efforts to reduce disparities.

**THE AFFORDABLE CARE ACT: NEW OPPORTUNITIES FOR DISPARITIES EFFORTS**

Data collection in a standard, uniform manner is important to identify and monitor disparities and to develop strategies for disparities-reduction efforts—and it is particularly important in the era of the Affordable Care Act, which offers concrete opportunities to reduce disparities when they are identified. Efforts to strengthen data collection include section 4302 of the Affordable Care Act (Understanding Health Disparities: Data Collection and Analysis), which focuses on data-collection standards for race, ethnicity, sex, primary language, and disability status for Health and Human Services–sponsored surveys and programs in which participants self-report such data. The new data standards allow for consistent collection in these five demographic areas and therefore have the potential to tremendously bolster disparities monitoring and policy efforts in the United States.

Data from the US Department of Health and Human Services (HHS) are the primary source used to monitor the nation’s health. These data have served to identify health disparities, to monitor progress toward disparities reduction and elimination, and to guide policy and research. Data on issues such as insurance coverage, preventive care, access to and quality of care, mental health services utilization, and medical expenditures are collected by HHS surveys, and the data are
used to provide national, and often subnational, estimates of these measures. As implementation of the Affordable Care Act moves forward, these areas are likely to be affected; how they are affected will be central to assessing their impact on population subgroups.

HHS data collection occurs through a family of related surveys, of which a few are described below. The National Health Interview Survey (NHIS), the flagship health survey conducted by HHS, collects data on a broad range of health topics that are used for characterizing individuals with various health problems and identifying barriers to accessing and using appropriate health care. The NHIS has the largest sample of all major HHS surveys, with data on ~87,500 individuals collected annually (65). A significant strength of this survey lies in the ability to display these health characteristics by many demographic and socioeconomic characteristics. The National Health and Nutrition Examination Survey (NHANES) combines interviews and physical examinations and is designed to assess the health and nutritional status of adults and children in the United States (64). National data on health care quality and access as well as expenditure data are collected via the Medical Expenditure Panel Survey (MEPS) (1). HHS also sponsors data collections to support health monitoring at the state level. The Behavioral Risk Factor Surveillance System (BRFSS), for example, is used to monitor state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality, and these data are used for planning, initiating, supporting, and evaluating health-promotion and disease-prevention programs. National data are also collected for key topical areas and special populations (13). For instance, the National Survey on Drug Use and Health (NSDUH) is the primary source of information on US adolescents’ and adults’ use of illicit drugs, alcohol, and tobacco (88). Additionally, the Medicare Current Beneficiary Survey (MCBS) is a nationally representative survey of Medicare beneficiaries that includes information on socioeconomic and demographic characteristics, health status and functioning, health care use, and expenditures (78). A complete list of major surveys can be found in the Guide to HHS Surveys and Data Resources (68). By standardizing the collection of demographic data across these surveys, the new data-collection standards will allow appropriate comparisons across the data collected in these surveys by demographic variables.

Prior to the Affordable Care Act 4302 standards, these surveys neither collected data on race and ethnicity at comparable levels of specificity, nor used consistent collection methods for data on primary language and disability status. This has limited researchers’ ability to track the status of health and health care for diverse populations in a uniform way across HHS data systems. The new standards, implemented in October 2011 (28), provide additional granularity for race and ethnicity data collections and, for the first time, provide requirements for primary language and disability status data collections.

HHS DATA-COLLECTION STANDARDS FOR RACE, ETHNICITY, SEX, PRIMARY LANGUAGE, AND DISABILITY STATUS

In this section, we present the new data-collection standards and review the rationale for developing these standards and the process of implementation, highlighting select survey enhancements. We also provide examples of how the standards could help track the impact of key Affordable Care Act provisions related to coverage, access, and quality of care for diverse groups within the United States.

Data Standard Development Process

Section 4302 of the Affordable Care Act requires the Secretary of HHS to establish data-collection standards for race, ethnicity, sex, primary language, and disability status. As part of Affordable Care

Dorsey et al.

Changes may still occur before final publication online and in print
Act implementation and data standard development, the HHS Data Council—the senior data and statistical advisory body for HHS—reviewed the status of existing federal data-collection standards; assessed the adequacy of prior testing and the quality of the data produced in prior surveys; examined reports related to data collection and standardization such as the IOM report, Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement (86); and reviewed the experience of federal statistical and data-collection agencies in collecting and analyzing demographic data.

HHS then established the following criteria to develop data standards that would (a) work well in population health surveys, as demonstrated by strong supporting evidence, such as cognitive testing of survey items; (b) serve as minimum requirements for data collection, with HHS agencies permitted to include additional detail on these topics as desired; and (c) comply with any standards mandated by the OMB (Figure 1). Data standards apply to person-level data collected in population-based health surveys in which respondents provide self-reported information or a knowledgeable proxy either provides information about the respondents or responds for all persons in a household (74). Below, we describe the new data-collection standards for race, ethnicity, sex, primary language, and disability status.

Race and Ethnicity
The starting point for the HHS race and ethnicity data standards was the 1997 OMB minimum standards. OMB unveiled them after a comprehensive public engagement process and extensive field testing (73) to identify key cultural and social groups for reporting and civil rights monitoring (72). Since their establishment, the OMB standards represented the minimum required to maintain, collect, and present data on race and ethnicity for all federal reporting purposes (72). Specifically, these OMB standards established minimum categories for race and Hispanic ethnicity, with five race categories (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White) and two ethnicity categories (Hispanic or Latino and Not Hispanic or Latino) (Figure 1). Individuals were also permitted to select more than one race.

The new HHS standards for race and ethnicity build on the OMB minimum standard and include additional granularity for self-reported categories beyond the existing federal standard (Figure 1) (35, 44). HHS used the American Community Survey (ACS), an ongoing survey conducted by the Census Bureau that provides community-level data on demographic, social, economic, and housing characteristics, and Decennial Census questions as the basis for this standard because the Census Bureau has already undertaken a very rigorous process to develop more granular questions on race and ethnicity (35). The race and ethnicity categories for the ACS and recent Decennial Census have been tested and structured to increase response rates, validity, and reliability. Evaluation studies dating back to the 1970 census as well as more extensive research studies conducted shortly after the 1980, 1990, and 2000 censuses have examined item nonresponse rates, different response types, and the editing and allocation methods to the question on race and Hispanic origin. Findings from these studies, as well as the 2005 National Census Test, have demonstrated the reliability of these questions.

The new HHS data standards are consistent with other federal data surveys (35, 44). This alignment provides a more comprehensive profile of populations because one can combine, for example, fine-grained economic and social data from the US Decennial Census or ACS data with health data provided by HHS surveys (91, 90). The newly adopted HHS data standards for race and ethnicity include additional specificity, but they also have categories that can be consolidated or “rolled up” to the current OMB standard (Figure 1). Many large HHS surveys, such as the NHIS,
<table>
<thead>
<tr>
<th>Data element</th>
<th>Data standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Are you Hispanic, Latino/a, or Spanish origin? (one or more categories may be selected)</td>
</tr>
<tr>
<td></td>
<td>a. ___ No, not of Hispanic, Latino/a, or Spanish origin</td>
</tr>
<tr>
<td></td>
<td>b. ___ Yes, Mexican, Mexican American, Chicano/a</td>
</tr>
<tr>
<td></td>
<td>c. ___ Yes, Puerto Rican</td>
</tr>
<tr>
<td></td>
<td>d. ___ Yes, Cuban</td>
</tr>
<tr>
<td></td>
<td>e. ___ Yes, another Hispanic, Latino/a, or Spanish origin</td>
</tr>
<tr>
<td>Race</td>
<td>What is your race? (one or more categories may be selected)</td>
</tr>
<tr>
<td></td>
<td>a. ___ White³</td>
</tr>
<tr>
<td></td>
<td>b. ___ Black or African American³</td>
</tr>
<tr>
<td></td>
<td>c. ___ American Indian or Alaska Native³</td>
</tr>
<tr>
<td></td>
<td>d. ___ Asian Indian</td>
</tr>
<tr>
<td></td>
<td>e. ___ Chinese</td>
</tr>
<tr>
<td></td>
<td>f. ___ Filipino</td>
</tr>
<tr>
<td></td>
<td>g. ___ Japanese</td>
</tr>
<tr>
<td></td>
<td>h. ___ Korean</td>
</tr>
<tr>
<td></td>
<td>i. ___ Vietnamese</td>
</tr>
<tr>
<td></td>
<td>j. ___ Other Asian</td>
</tr>
<tr>
<td></td>
<td>k. ___ Native Hawaiian</td>
</tr>
<tr>
<td></td>
<td>l. ___ Guamanian or Chamorro</td>
</tr>
<tr>
<td></td>
<td>m. ___ Samoan</td>
</tr>
<tr>
<td></td>
<td>n. ___ Other Pacific Islander</td>
</tr>
<tr>
<td></td>
<td>Asian⁴</td>
</tr>
<tr>
<td></td>
<td>Native Hawaiian or other Pacific Islander⁵</td>
</tr>
<tr>
<td>Sex</td>
<td>What is your sex?</td>
</tr>
<tr>
<td></td>
<td>a. ___ Male</td>
</tr>
<tr>
<td></td>
<td>b. ___ Female</td>
</tr>
<tr>
<td>Primary language</td>
<td>How well do you speak English? (5 years and older)</td>
</tr>
<tr>
<td></td>
<td>a. ___ Very well</td>
</tr>
<tr>
<td></td>
<td>b. ___ Well</td>
</tr>
<tr>
<td></td>
<td>c. ___ Not well</td>
</tr>
<tr>
<td></td>
<td>d. ___ Not at all</td>
</tr>
<tr>
<td></td>
<td>Data collection for language spoken (optional)</td>
</tr>
<tr>
<td></td>
<td>1. Do you speak a language other than English at home? (5 years and older)</td>
</tr>
<tr>
<td></td>
<td>a. ___ Yes</td>
</tr>
<tr>
<td></td>
<td>b. ___ No</td>
</tr>
<tr>
<td></td>
<td>For persons speaking a language other than English (answering yes to the question above):</td>
</tr>
<tr>
<td></td>
<td>2. What is this language? (5 years and older)</td>
</tr>
<tr>
<td></td>
<td>a. ___ Spanish</td>
</tr>
<tr>
<td></td>
<td>b. ___ Other language (identify)</td>
</tr>
</tbody>
</table>

¹ Not Hispanic or Latino
² Hispanic or Latino
³ Asian
⁴ Native Hawaiian or other Pacific Islander
⁵ Not Hispanic or Latino

Continued on next page
Continued from previous page

<table>
<thead>
<tr>
<th>Data element</th>
<th>Data standard</th>
</tr>
</thead>
</table>
| Disability status | 1. Are you deaf, or do you have serious difficulty hearing?  
  a. ___ Yes  
  b. ___ No  
  2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?  
  a. ___ Yes  
  b. ___ No  
  3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years and older)  
  a. ___ Yes  
  b. ___ No  
  4. Do you have serious difficulty walking or climbing stairs? (5 years and older)  
  a. ___ Yes  
  b. ___ No  
  5. Do you have difficulty dressing or bathing? (5 years and older)  
  a. ___ Yes  
  b. ___ No  
  6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (15 years and older)  
  a. ___ Yes  
  b. ___ No |

*New HHS data standard included in brackets corresponds to and can be rolled back into this Office of Management and Budget (OMB) category (73).*

*Corresponds to the present OMB standard for this category (73).*

**Figure 1**

New Health and Human Services (HHS) data standards for race, ethnicity, sex, primary language, and disability status. Data in this table are published on the HHS website (http://minorityhealth.hhs.gov/templates/content.aspx?ID=9227&lvl=2&lvlID=208) and in part in Reference 28.

NSDUH, and the MEPS, had previously implemented a more granular strategy, particularly for Hispanic and Asian subpopulations. However, whereas slight differences in subcategories had limited the ability to compare racial and ethnic groups between surveys, the new standards create uniform categories to facilitate these comparisons. The additional granularity provided by the new standards will be a first for some major surveys, such as the BRFSS. Thus, the new data standards will provide additional categories from which racial and ethnic differences in health and health care can be explored in a uniform way and among subgroups using all major population surveys.

The practical implications of expanded categories and the importance of obtaining additional specificity for population subgroups to track the long-term implementation of the Affordable Care Act can be seen in several examples. In particular, reports have suggested the extent of no insurance varies considerably within Asian American and Pacific Islander subgroups, with rates of 6.6% for Japanese Americans, 10.9% for Filipino Americans, 11.8% for Asian Indian Americans, 13.4% for Chinese Americans, 16.7% for Native Hawaiian and Pacific Islander Americans, 19.8% for Vietnamese Americans, and 25.5% for Korean Americans (17). The new data standards will provide additional categories through which racial and ethnic differences in health and health...
care can be explored in a uniform way, among subgroups, for all major population surveys. It is important to note, that while new data standards provide additional granularity for data collections, reporting of such data is possible only when sample size permits statistically reliable estimates. Pooling survey years is one method used to increase sample size for data reporting. Statistical agencies may employ techniques to increase sample size, such as oversampling respondents from populations subgroups (such as racial and ethnic groups), when feasible (36).

Sex

Data on sex have been collected in the United States longer than have data on any other demographic variable, beginning with the first Decennial Census in 1790, and in virtually all forms of health data collections, including surveys, administrative forms, medical records, and other federal collections (89). Before the new data standards were created, and in the absence of a required standard for collecting data on sex for HHS surveys, the demographic data conventions of the Census Bureau were generally used (91, 90). Section 4302 of the Affordable Care Act represents the first opportunity to standardize the definition of this variable. After consideration, the category of sex was defined as current biologic sex (male or female) for the present data standard development process; sexual orientation and gender identity are treated as separate and distinct concepts. Through a separate and concurrent process, HHS has recently completed a data testing and progression plan for questions on sexual orientation while exploring options for collecting data on gender identity. As a result, HHS has added questions on sexual orientation to the NHIS.

The new standard will facilitate and preserve the uniform collection of data on sex for the monitoring of differences in health and health care between men and women. The new standard enhances continued examination of critical sex-specific differences in access, utilization, and quality of care. Under the Affordable Care Act, women have increased access to care, including annual well-woman visits, mammograms, and breastfeeding support, with no out-of-pocket costs (21, 40, 41). The Affordable Care Act also expands opportunities for insurance coverage for low-income single individuals, and, for the first time, many low-income men will be eligible for health insurance coverage. Thus, as implementation of the Affordable Care Act continues, the new standard heightens the ability to track and document sex-specific estimates of self-reported health and health care.

Primary Language

Language considerations affect health status, access to care, and health outcomes at the population level. And in the health care setting, growing evidence suggests that patient–provider language concordance results in greater patient understanding, better adherence to medication, more health education, and better health outcomes (25). In general, language assessment generally takes four factors into consideration: (a) English proficiency, (b) spoken language, (c) language spoken at home, and (d) written language (86). However, even though HHS surveys to date have almost always reported the language in which the interview was conducted, few have reported the interviewees’ preferred spoken language or English proficiency. Such specificity is relevant because limited English proficiency has been associated with disparities related to health care access and the delivery and quality of care (97). To date, population-level data to identify access to and quality of care and preventive services among persons with limited English proficiency have been scarce (14).

Themes of limited English proficiency are also critically relevant to assessing discrimination by national origin under Title VI of the Civil Rights Act of 1964; federal policies state that “reasonable steps” need to be taken for persons with limited English language proficiency to have “meaningful
access” to programs (101). At a minimum, establishing whether an individual speaks English less than “very well” is essential for health communication and health literacy (70). Hence, the new minimum data standard for primary language is a measurement of English proficiency, which has been used by the Census Bureau since 1980 (25, 81). This new minimum standard applies to population surveys with self-reported data; HHS agencies have the option to collect data on the language spoken by respondents. In such instances, HHS recommends collecting data on the language spoken at home, with survey items adapted from questions currently being used by the ACS. However, for clinical data collected at the point of health care delivery, it is more appropriate to both assess English proficiency and also record the language spoken.

With these changes, HHS surveys will, for the first time, regularly collect respondent-reported data on language. The new language data standard is an important enhancement to HHS data collections, in particular as the nation implements key provisions related to increasing access and preventive services of the Affordable Care Act. Prior to enacting the standard, language data were rarely self-reported or used as variables to report national health data, despite the fact that persons with limited English proficiency are less likely to have insurance or access to primary and preventive care services compared with individuals proficient in English (14, 103). The data standard for primary language provides new opportunities for tracking disparities by language and should make data available to monitor the impacts of the Affordable Care Act for groups with low English proficiency.

**Disability Status**

People with disabilities experience more health care disparities, such as lower rates of screening and more difficulty accessing services, than do people without disabilities (47, 87). In the absence of a department-wide standard, HHS surveys have assessed disability status in a variety of ways. The number of questions, the wording of questions and response categories in survey items, and the type and severity of disability assessed have all varied. For instance, the NHIS has traditionally collected extensive information beyond the newly adopted HHS minimum standard using a special disability supplement to obtain detailed information about disability and health status. Meanwhile, the MCBS has been collecting data on a slightly different question set than those in the new standard. Also, in the past, HHS’s ability to provide a consistent report of functional disability status in the United States may have been limited by surveys with fewer items than the new standard, which may have missed certain domains of functional status.

The new data standard, which will have a six-item minimum, will allow HHS to identify disparities in disability status across data systems in a consistent way. The six items reflect the International Classification of Functioning, Disability, and Health (ICF), an innovative way for health care providers treating disabled patients to classify health and functioning. Initially endorsed on May 22, 2001, by the 54th World Health Assembly for international use, the ICF offers a two-part framework: (a) functioning and disability, and (b) contextual factors (100). The question set defines disability from a functional perspective to monitor disparities between disabled and nondisabled populations. After several rounds of cognitive testing and field testing, the six-item set of questions has been adopted by many federal data-collection systems (9). The OMB has encouraged federal agencies conducting similar population studies to use this set of questions, and the set is currently being used in surveys such as the ACS and NHIS.

The new data standard provides important uniformity for tracking health status and disparities for persons with disabilities. Surveys such as the NSDUH and the BRFSS will for the first time include these items. These additions will provide new opportunities for monitoring health among population subgroups by disability status. For example, persons with disabilities may be at higher
risk for substance abuse, and thus data on disability status from the NSDUH will provide valuable information in this area at the national level (71). Also, including the new disability status standard in the BRFSS will enhance the ability of that survey to produce state-level estimates on disability. HHS surveys may also collect additional data on disability status beyond the new standard.

The new disability status data-collection standard provides fresh opportunities to track health disparities between persons with and without disabilities. Starting in 2014, under the Affordable Care Act, persons with preexisting conditions, including disabilities, can no longer be excluded from coverage or charged higher premiums; this has the potential to improve access to care for persons with disabilities (42). The Affordable Care Act includes obesity screening and counseling for all adults, tobacco use screening for all adults, and smoking-cessation interventions for tobacco users as covered preventive services with no cost-sharing requirements. These provisions may be particularly critical because people with disabilities are much more likely to report being in fair or poor health, to use tobacco, to forgo physical activity, and to be overweight or obese (47). The new disability status data standard will enhance the ability to use existing surveys to more accurately examine the impacts of the Affordable Care Act on persons with disabilities.

Implementation

Beginning in 2011, new major HHS surveys began to use the new standards, with existing surveys implementing them at the time of the next major revision. The HHS Data Council will track and monitor progress in implementing data standards in HHS-sponsored surveys over time. Agencies sponsoring major surveys will provide updates on changes related to new or revised measures related to the data-collection standards on their respective websites. Implementing the five new standards (race, ethnicity, sex, language, and disability status) will require different methods for the various HHS surveys, and implementation will take place in phases for many of these surveys. Revisions will include adding new questions to address standards not already included in data collection. For surveys that are already collecting the data standard element, it may mean revising survey questions, response options, or both. In practice, implementation of the standards will have to address multiple and potentially competing de facto standards in cases where surveys have asked certain questions in a specific way over a period of years and will need to assess any effect of the new questions on established trends. Accordingly, implementation poses several methodological challenges, such as alignment with existing items that collect the same data, and thus full implementation is expected to take several years. HHS will also explore and employ strategies to maintain the quality and integrity of the data as standards are implemented.

Future Directions

Because the new HHS standards apply to national population-based surveys, future efforts should also focus on resolving issues relevant to administrative data (such as data captured at the time of enrollment in a program or data collected from a medical record), clinical data (collected as part of clinical care), and research data (collected from participants in research studies). Consistent collection of information will help ensure data are available to answer critical questions about health, health care, and associated disparities. For example, program participants may be concerned about providing demographic data at enrollment if they do not understand how the information will be used. Also, health care professionals may want electronic health records (EHR) systems that efficiently record specific information on the preferred language for patients. HHS is addressing such concepts and approaches, where appropriate, for administrative and clinical purposes. Such work could align and complement ongoing work on EHR certification and further development
of meaningful-use criteria for EHR. In addition, exploring the alignment of guidance provided to investigators for reporting demographic data for participants enrolled in research studies to the new data standards may provide additional opportunities to compare findings from research studies with data collected through national surveys, which could inform the future development of both.

Future work will also address additional areas of section 4302, such as obtaining health- and health care–related data for rural and frontier populations and developing measures to assess the provider-level access to care for persons with disabilities. Through a separate provision in section 4302, the Centers for Medicare and Medicaid Services (CMS) is partnering with states to improve the collection of demographic data by Medicaid and the Children’s Health Insurance Program (CHIP) to inform local efforts to reduce health disparities. In the fall of 2011, the CMS provided its first update to Congress on this work, Approaches for Identifying, Collecting and Evaluating Data on Health Disparities in Medicaid and CHIP, and has begun a dialogue with the states on these national standards (80).

CONCLUSION

The promulgation of data-collection standards for race, ethnicity, sex, primary language, and disability status strengthens HHS data collections and bolsters efforts to monitor disparities. It will also facilitate more detailed understanding of the impacts of the Affordable Care Act on diverse US population subgroups. These new standards build on prior federal standards for race and ethnicity and create new standards for primary language, sex, and disability status. They will also catalyze future efforts to identify within-group differences, such as those among Asian and Latino subgroups, and disparities among people with disabilities. Also, new language standards can better identify groups with limited English proficiency and accelerate implementation of health communication and health literacy efforts nationwide (52). Researchers will be better able to track systematically how reform efforts and other activities affect racial and ethnic subpopulations, individuals who speak a language other than English, and those with disabilities. Such information can then be used to develop policies and programs to better target disparities.

The Affordable Care Act enacted comprehensive health insurance reforms, and the law contains specific provisions to improve federal, state, and local efforts to address the health concerns of underserved communities; increase opportunities for health insurance coverage; improve access to care; and, as a result, contribute to progress toward health equity. The Affordable Care Act requires health plans to cover certain recommended preventive services without cost-sharing requirements; support new investments in managing chronic diseases, including those that disproportionately and adversely affect minority communities; expand initiatives to increase diversity in the health care professions; increase funding for community health centers; and expand opportunities for health insurance coverage for millions of Americans. With the simultaneous enactment of these provisions and section 4302, we will have the potential to track macrolevel progress in reducing disparities through the Affordable Care Act and other efforts.

The new data standards may also serve as a model for advancing improved data collection in agencies other than HHS and beyond the federal sector. Measurement of the Affordable Care Act’s impacts should take place at various levels in the private and public sectors. Ultimately, the HHS efforts noted here could also serve to unify similar data standard efforts that currently involve states and cities, hospitals, providers, policy makers, health care organizations, health plans, and accreditation and standards-setting organizations. The sum of all these efforts should revitalize efforts to better identify and address disparities, improve quality, and improve our ability to monitor the long-term effects of the Affordable Care Act on diverse populations.

www.annualreviews.org • Data-Collection Standards for Disparities

Changes may still occur before final publication online and in print
DISCLOSURE STATEMENT

The authors are not aware of any affiliations, memberships, funding, or financial holdings that might be perceived as affecting the objectivity of this review.

ACKNOWLEDGMENTS

At the time of drafting, Drs. Dorsey and Glied were affiliated with the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, and Dr. Clancy was affiliated with the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services.

The authors also thank Jim Scanlon, Dale Hitchcock, and Susan Queen for their careful review of this manuscript.

LITERATURE CITED


Dorsey et al.


